



The National Long-Term Care
Ombudsman Resource Center

MODULE TWO

The Resident and the
Resident Experience

TRAINER GUIDE

January 2025

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Module 2 State-Specific Information

The list below outlines state-specific information for trainers to discuss, provide a link to, or add directly to the Trainer Guide, Trainee Manual, and/or PowerPoints. When you get to the point in the training where you need to discuss, include a link to, or add state-specific information, you will see a **bold, blue arrow (→)** and a brief description of what to include.

→ State-Specific Information

Section 2 Resident Demographics

- Share state-specific nursing facility demographics. The [Minimum Data Set \(MDS\) 3.0 Resident Assessment Instrument \(RAI\) Frequency Report](https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/Minimum-Data-Set-3-0-Public-Reports/Minimum-Data-Set-3-0-Frequency-Report)¹ summarizes information from the MDS for residents currently in nursing facilities. The MDS 3.0 is a federally mandated assessment of all residents in Medicare and Medicaid certified nursing facilities. Nursing facilities conduct MDS assessments upon admission, throughout the resident's stay, and upon discharge. Data from the assessments is transmitted electronically using the MDS national database at CMS. You can search for information by state and use it for demographics.
- Provide state-specific information for residential care communities:
 - Types of residential care communities
 - Any requirements for providing specific services for residents (e.g., dementia care)
 - Demographic data
- Review state-specific information about individuals with intellectual and developmental disabilities and where individuals with such disabilities live (e.g., in the community, Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID), group homes, or personal care homes).

¹ <https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/Minimum-Data-Set-3-0-Public-Reports/Minimum-Data-Set-3-0-Frequency-Report>

Section 1:

Welcome and Introduction

Welcome

Trainer's Note: Allow at least 15 minutes for Section 1.

Begin the session by welcoming the trainees back to the training and thanking them for their continued interest in the program. Make sure everyone introduces themselves – even if they come late.

To begin, please share:

- *Your name*
- *Where you are from*
- *One thing you learned from Module 1 - something that really stuck with you or surprised you*
- *What you hope to learn since the last module*

After introductions, thank the trainees for their information and explain any housekeeping items that need to be addressed including the time frame of the training day, breaks, location of restrooms, refreshments, etc. Ask the trainees to speak up if they have any questions throughout the training.

Welcome to Module 2, ***The Resident and the Resident Experience***. Thank you for being here to learn more about the Long-Term Care Ombudsman program and the certification process. Since this Module focuses on the resident and the resident experience, you will see several quotes from residents throughout the manual. The quotes are from actual residents, but the names have been changed for purposes of confidentiality. To amplify the voices of the residents, other than for length, the quotes have not been edited.

Module 2 Agenda

Trainer's Note: The timeframes for each Section are approximate. Allow at least 3.25 hours for this session.

- Section 1: Welcome and Introduction *(15 minutes)*
- Section 2: Resident Demographics *(45 Minutes)*
- Section 3: The Resident Experience *(45 Minutes)*
- BREAK** *(10-15 Minutes)*
- Section 4: Common Health Experiences *(60 Minutes)*
- Section 5: Conclusion *(15 Minutes)*

Module 2 Learning Objectives

***Trainer's Note:** Be mindful of the sensitive topics discussed in this Module. The discussion could trigger unexpected emotions from the trainees due to a personal experience. Sometimes when this happens people either shut down or overshare. Pay close attention to the trainees and if you notice someone having a hard time, either take a break or arrange to talk with them after the session or both. If someone begins to overshare and their experiences start to take over the discussion, politely and respectfully express the need to move on with the material and offer them time to speak with you privately after the training. Review the learning objectives with the trainees.*

After completion of Module 2, you will understand:

- Who lives in long-term care facilities
- Why people enter long-term care
- Why people stay in long-term care
- The impact of loss when residents enter long-term care
- Common diagnoses and their impact on residents and importance to the Long-Term Care Ombudsman program (LTCOP)
- Common health concerns in long-term care

Module 2 Key Words and Terms

The key words and terms are defined relative to Ombudsman program practices and are found throughout this Module. Take a moment to familiarize yourself with this important information.

Activities of Daily Living (ADLs) – Basic tasks and fundamental skills necessary to independently care for oneself, such as eating, bathing, and mobility.

Centers for Medicare & Medicaid Services (CMS) – A division within the U.S. Department of Health and Human Services, CMS administers the nation's major healthcare programs including Medicare and Medicaid.

Demographics – Statistical data relating to the population and particular groups within it. For the purposes of this training, the demographics used are from federal resources. States may include their own state-specific data from state resources.

Home and Community-Based Services (HCBS) – Provides consumers needing long-term care services more choices in where and how they receive those services.²

Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) – The ICF/IID benefit is an optional Medicaid benefit; however, all states offer this. ICF/IID provide active treatment for individuals with intellectual disabilities and other related conditions. Residents in ICF/IID may be non-ambulatory, have seizure disorders, mental illness, visual or hearing problems, or a combination of conditions. Currently, the Ombudsman program in very few states either visit or respond to complaints from ICF/IID.³

Minimum Data Set 3.0 (MDS, MDS 3.0) – A federally mandated assessment of all residents of Medicare and Medicaid certified nursing homes. MDS assessments are conducted upon admission, throughout the resident's stay, and upon discharge. The data from the assessments are transmitted electronically using the MDS national database at CMS.⁴

Office of the State Long-Term Care Ombudsman (Office, OSLTCO) – As used in sections 711 and 712 of the Act, means the organizational unit in a State or territory which is headed by a State Long-Term Care Ombudsman.⁵

Ombudsman – A Swedish word meaning agent, representative, or someone who speaks on behalf of another. For the purposes of this manual, the word “Ombudsman” means the State Long-Term Care Ombudsman.

² *Home and Community Based Services* National Long-Term Care Ombudsman Resource Center
<https://ltombudsman.org/home-and-community-based-services>

³ <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/ICFIID>

⁴ <https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/Minimum-Data-Set-3-0-Public-Reports/Minimum-Data-Set-3-0-Frequency-Report>

⁵ 45 CFR Part 1324 Subpart A §1324.1 Definitions

Representatives of the Office of the State Long-Term Care Ombudsman

(Representatives) – As used in sections 711 and 712 of the Act, means the employees or volunteers designated by the Ombudsman to fulfill the duties set forth in §1324.19(a), whether personnel supervision is provided by the Ombudsman or his or her designees, or by an agency hosting a local Ombudsman entity designated by the Ombudsman pursuant to section 712(a)(5) of the Act.⁶

Residential Care Community (RCC) – A type of long-term care facility as described in the Older Americans Act (Act) that, regardless of setting, provides at a minimum, room and board, around-the-clock on-site supervision, and help with personal care such as bathing and dressing or health-related services such as medication management. Facility types include but are not limited to, assisted living; board and care home; congregate care; enriched housing programs; homes for the aged; personal care homes; adult foster/ family homes; and shared housing establishments that are licensed, registered, listed, certified, or otherwise regulated by a state.⁷

Serious Mental Illness – A mental, behavioral, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities.⁸

Skilled Nursing Facility or Nursing Facility – Also known as a “nursing home,” is a certified facility that provides skilled nursing care for residents who require medical or nursing care rehabilitation or provides health-related care and services to individuals who, because of their mental or physical condition, require care and services (above the level of room and board) which can be made available to them only through institutional facilities.⁹ For the purposes of this training and to be consistent with the National Ombudsman Reporting System (NORS), we use the term “nursing facility” for both skilled nursing facilities and nursing facilities.¹⁰

State Long-Term Care Ombudsman (Ombudsman, State Ombudsman) – As used in sections 711 and 712 of the Act, means the individual who heads the Office and is responsible personally, or through representatives of the Office, to fulfill the functions, responsibilities, and duties set forth in §1324.13 and §1324.19.¹¹

State Long-Term Care Ombudsman program (Ombudsman program, the program, LTCOP) – As used in sections 711 and 712 of the Act, means the program through

⁶ 45 CFR Part 1324 Subpart A §1324.1 Definitions

⁷ CA-04 02 Residential Care Community Table 1 Part C Case and Complaint Definitions

https://ltcombudsman.org/uploads/files/support/NORS_Table_1_Case_Level_10-31-2024.pdf

⁸ National Institute of Mental Health retrieved from www.nimh.nih.gov

⁹ This definition is a combination of Requirements for, and assuring Quality of Care in, Skilled Nursing Facilities, Section 1819(a) of the Social Security Act [42 U.S.C. 1395i-3(a)]

https://www.ssa.gov/OP_Home/ssact/title18/1819.htm and Requirements for Nursing Facilities, Section 1919(a) of the Social Security Act [42 U.S.C. 1396r(a)] https://www.ssa.gov/OP_Home/ssact/title19/1919.htm

¹⁰ NORS Table 1 https://ltcombudsman.org/uploads/files/support/NORS_Table_1_Case_Level_10-31-2024.pdf

¹¹ 45 CFR Part 1324 Subpart A §1324.1 Definitions

which the functions and duties of the Office are carried out, consisting of the Ombudsman, the Office headed by the Ombudsman, and the representatives of the Office.¹²

Subsection Symbol (§) – The subsection symbol is used to denote an individual numeric statute or regulation (rule).

¹² 45 CFR Part 1324 Subpart A §1324.1 Definitions

Section 2:

Who Lives in Long-Term Care Settings and Why?

If you're a caregiver, you don't just insert a hearing aid for a hearing-deprived resident; you don't just give a shower to a manually disabled resident; you don't just wipe a totally dependent resident. In short, you do more than assist a resident with performing the Activities of Daily Living. **You become the human bridge that carries a trace of dignity to the helpless, that empathizes with their inability and uncertainty.**

- David

When many people think about residents, they imagine older individuals with a variety of ailments associated with aging, who are bedridden or immobile. Sometimes lost is the realization that residents vary in the same respect as individuals who live in the community. Residents have a variety of backgrounds, life experiences, and roles, such as: mother, father, friend, sibling, son, daughter, teacher, nurse, doctor, engineer, coach, farmer, and social worker. The list goes on and on. Some residents had a hard life, some were abused as a child or an adult. Some residents are veterans, some have seen combat, some are Holocaust survivors, and some marched for civil rights and/or made great contributions to their communities. Each one of us can be found in the face of a resident.

Trainer's Note: *Show the video below and let the trainees know the video was made to inform residents about diversity. After showing the video, ask the following questions.*



Watch the video titled [LTC Informational Series Video 9 – Diversity in Long-Term Care Facilities](#) and answer the following questions.¹³

1. According to the video, what is the facility's responsibility in terms of discrimination?

Answer: *"To ensure that no one is discriminated against at any time when they are a resident of that facility."*

2. According to the video, what is the overall goal of every long-term care facility?

Answer: *"To provide a homelike atmosphere for all of their residents. Acknowledge the fact that the residents define homelike according to their own terms and must be allowed to do so without the fear of judgement or critique of others."*

Myths and Stereotypes about Individuals Living in Long-Term Care

Trainer's Note: *Allow at least 60 minutes to cover Section 2. Use the chart in Figure 1 to explain common myths and stereotypes about people who live in long-term care facilities. Draw from your experiences – but you do not need to provide an example for each myth/stereotype or reality. There are examples listed below the chart you can use if needed.*

¹³ Southwestern Commission LTC Informational Series Video 9 – Diversity in Long-Term Care Facilities
https://www.youtube.com/watch?v=wYeyXzRSwwl&list=PLSu_zY6vP6REXfvjgVf7E-F9CG2K_9P-F&index=11

There are some common myths and stereotypes about older adults and persons living with disabilities¹⁴ in long-term care facilities. In reality, residents are not much different from those living in the community at-large. Residents have desires, abilities, and the need to have a sense of purpose. Residents are from all walks of life, are young and old, with or without disabilities. Just as with other populations, it is damaging to stereotype people who live in long-term care facilities.



COMMON MYTHS AND STEREOTYPES

Figure 1

Myth/Stereotype	Reality
Residents are not connected to what is going on around them. Residents lose interest in life and become more introspective and withdrawn.	Residents are interested in meaningful relationships. People important to the resident may have died or disengaged from the resident, but that does not mean the resident isn't interested in connecting with others.
Residents are child-like and should be treated as such.	Residents are adults and should be treated with dignity and respect.
Residents are dependent and want someone to take care of all their needs. People with disabilities always need help.	Most residents maintain abilities and want to care for themselves as much as possible. Most residents do not want to be totally dependent on others to meet their needs. In fact, many residents are not fully dependent and want to be as independent as possible.
Older people don't participate in sexual activity. Most people with disabilities cannot have sexual relationships.	Need for sexual expression and intimacy continues throughout life. Anyone can have a sexual relationship by adapting sexual activity. Sexuality is a basic human need and the choice to participate in sexual acts belongs to the resident.
Younger people do not reside in long-term care facilities.	There are younger residents who live in long-term care facilities. In fact, nearly 17% ¹⁵ of nursing facility residents are under 65 years old.
People with mental illnesses are not admitted into nursing facilities.	There are residents who live in long-term care facilities with a range of mental illness diagnoses.
Old people are unproductive and set in their ways. They have already made their contribution to society.	The need to feel a sense of purpose in life does not change once one becomes a resident. Residents need to have a reason to wake up in the morning and to feel useful and important. Growing older does not mean one no longer wants to learn.

¹⁴ Myths and Facts about People with Disabilities www.govst.edu

¹⁵ Minimum Data Set 3.0 Frequency Report retrieved from www.cms.gov

Residents are interested in meaningful relationships – People important to the resident may have died or disengaged from the resident, but that does not mean the resident isn't interested in connecting with others. Sometimes residents may appear disengaged and that could be due to difficulty hearing, seeing, remembering, or to the side-effects of medications.



Ken always appears disinterested in what is going on around him and does not talk to the other residents. During a doctor's appointment, the doctor finds a great deal of wax build-up in Ken's ears and cleans them out. Since his appointment, Ken is much more social with the other residents.

Residents are adults and should be treated with dignity and respect – Sometimes when people live in long-term care facilities others treat them as though they are children and don't treat them with the respect they deserve.



Howard is a former engineer and says he does not appreciate how staff call him "honey" and "sweetie," or tell him when to go to bed. He says he is not a child and does not want to be treated in that manner.

Most residents maintain abilities and want to care for themselves as much as possible – Often, residents help each other and will alert staff if their roommate or neighbor needs assistance.



Jan always looks out for her roommate, Ethel, who cannot communicate. Jan knows from the look on Ethel's face when she needs help and gets someone to help her.

***Trainer's Note:** If you need additional experiences to share with trainees you may want to read the book "Counting on Kindness – The Dilemmas of Dependency" by Wendy Lustbader, MSW. The stories shared are from individuals that rely on caregivers to show how it feels to be dependent on others.*

Need for sexual expression and intimacy continues throughout life – People often assume that older adults or adults with disabilities lose their desire to be intimate. Residents often have a desire for intimacy which can come in several different forms.



Two residents, Mae and George, become quite close and want to be alone with the door shut. Mae's daughter is extremely upset and vocal that it is outside of her mother's character to be alone with a man other than Mae's deceased husband. The daughter believes George is taking advantage of Mae. Mae is uncomfortable that her relationship with George has become a problem for her daughter and does not want to discuss it with her. Mae talks to the social service director and the representative and states she wants to spend alone time with George. Mae states she likes their intimate relationship.

There are younger people who live in long-term care facilities – A common misconception is that younger residents do not reside in long-term care facilities and if they do, it must be a result of an accident. While that may be the case with some residents, most younger residents in long-term care facilities reside there due to a chronic illness and/or mental illness. During this training you will learn about community options and services to help people live in the least restrictive setting possible.



Jimmy is 36 years old and lives in a Residential Care Community (RCC) because he is unable to manage his medications prescribed for his mental illness. He needs medication reminders and structure to support his mental health.

The need to feel a sense of purpose in life does not change once one becomes a resident – While declining health and disabilities can restrict a resident from doing what used to give them a sense of purpose, it does not mean that new activities cannot foster the same feelings of purpose.



An excellent example is found in an Arizona assisted living for memory care. The facility partners with a local animal shelter and residents are provided with the opportunity to feed and play with kittens who are in constant need of care. The residents feel a sense of purpose in taking care of the kittens. Residents who struggled to communicate verbally prior to the program suddenly began to talk.



Watch the video titled [Adorable Kittens & Seniors Come Together and Help Each Other](https://www.youtube.com/watch?v=W9A3Gxlvso8).¹⁶

1. What are your thoughts about the video?
2. Did your perceptions about the importance of feeling a sense of purpose change after watching the video?

Trainer's Note: Ask the following question: “Why is it important to talk about assumptions made about individuals living in long-term care?”

Responses should include: to check preconceived notions, to gain a clear understanding about the people we will be assisting, and/or to understand others' stereotypes.

¹⁶ Only Good TV, Adorable Kittens & Seniors Come Together and Help Each Other <https://www.youtube.com/watch?v=W9A3Gxlvso8>

Resident Demographics

Share state-specific nursing facility demographics. The Minimum Data Set (MDS) 3.0 Resident Assessment Instrument (RAI) Frequency Report¹⁷ summarizes information from the MDS for residents currently in nursing facilities. The MDS 3.0 is a federally mandated assessment of all residents in Medicare and Medicaid certified nursing facilities. Nursing facilities conduct MDS assessments upon admission, throughout the resident's stay, and upon discharge. Data from the assessments is transmitted electronically using the MDS national database at CMS. You can search for information by state and use it for demographics.

→ Provide state-specific information for residential care communities:

- Types of residential care communities
- Any requirements for providing specific services for residents (e.g., dementia care)
- Demographic data

***Trainer's Note:** If you have facilities in your area that primarily serve a specific demographic, share that information with the trainees. Point out the major differences and make sure to cover the percentages of residents aged 65 and younger.*

Not all long-term care facilities are nursing facilities. Module 3 provides detailed information about nursing facilities and the different types of residential care communities (RCCs).

RCCs are a type of long-term care facility as described in the Older Americans Act that, regardless of setting, provide at a minimum, room and board, around-the-clock on-site supervision, and help with personal care such as bathing and dressing or health-related services such as medication management. RCCs vary from state to state. Not all facilities provide the same level of support and services and some may specialize in certain areas (e.g., memory care). Entrance is determined through a series of assessments and evaluations (discussed in Module 3). With the development of assisted living facilities and other state-licensed homes, the number of residents has increased in RCCs and has decreased in nursing facilities.

The demographics of long-term care residents have changed over the years.¹⁸ While most residents are white females 85 years of age and older, it is not unusual for the

¹⁷ <https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/Minimum-Data-Set-3-0-Public-Reports/Minimum-Data-Set-3-0-Frequency-Report>

¹⁸ Centers for Disease Control *Table 1 Resident population, by age, sex, race, and Hispanic origin: United States, selected years 1950-2016* <https://www.cdc.gov/nchs/data/hus/2017/001.pdf>

LTCOP to work with residents who are under age 65, or from various cultures, backgrounds, and experiences.

The second largest age group living in long-term care facilities are people between the ages of 75 and 84 years old. Residents who are age 64 or younger are increasing in numbers and have become the fastest growing population in long-term care facilities.¹⁹

While most nursing facilities have this generational overlap of residents, the interests of the younger residents in terms of music, activities, and culture may be quite different than those of the older residents. Facilities may need to expand their activities calendars, rethink their menus, and offer activities that interest younger individuals.

Residents with Intellectual and Developmental Disabilities²⁰

→ *Review state-specific information about individuals with intellectual and developmental disabilities and where individuals with such disabilities live (e.g., in the community, Intermediate Care Facilities for Individuals with Intellectual Disabilities [ICF/IID], group homes, and personal care homes).*

Trainer's Note: Not all Ombudsman programs visit facilities such as Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID). However, the Ombudsman program assists residents in nursing facilities and residential care communities who may have intellectual or developmental disabilities. Share an example of your program's experience working with this population and talk about programs and services that support community living rather than institutional care.

People with developmental disabilities (DD) may have difficulties with things such as speaking, learning, caring for themselves, moving around, making decisions, living independently, and making and managing money. Their difficulties start before age 22. They continue throughout life and are severe enough that the person needs ongoing supports.

Intellectual disability (ID) begins before age 22. People with ID have trouble learning and solving problems. They also have difficulties with practical skills such as dressing or shopping, social skills such as making and keeping friends and keeping others from hurting them, and with skills such as reading and doing math.

¹⁹ The Society for Post-Acute and Long-Term Care Medicine: *The Younger Adult in the Long-Term Care Setting* <https://paltc.org/product-store/younger-adult-long-term-care-setting>

²⁰ Most of the information in this section has been adapted from Administration for Community Living: *30 Years of Community Living for Individuals with Intellectual and/or Developmental Disabilities* <https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/30%20Years%207-13-21.pdf>

In the United States, about 2.3% of the people have ID/DD. About 7 in 100 children have ID/DD. Some children no longer have significant disabilities by the time they are adults. Fewer than 1 in 100 adults have ID/DD.

Historically, doctors and teachers told parents that institutions were the best place for people with ID/DD to live, learn, and be safe. But many families kept their children at home. Many professionals believed that people with ID/DD could not learn, hold a job, or live with their families. Beginning in the 1960's many laws passed that supported the rights of persons with intellectual and developmental disabilities including the Developmental Disabilities Assistance and Bill of Rights Act, the Individuals with Disabilities Education Act, The Americans with Disabilities Act and the Supreme Court's Olmstead decision, to name a few. These laws support and require equal access in education, the ability to live in a community, and equal access to health care and services.

Federal laws and policies continue to require supportive services in the least restrictive settings. Data indicates that in response to these changes:

- Four of every five people with ID/DD who lived in an institution in 1987 moved to a community home by 2017.
- The number of people with ID/DD supported to work in community jobs increased from 33,000 in 1987 to 135,000 in 2017.
- Medicaid spending to support people with ID/DD increased by three and a half times (from \$15.7 billion to \$55.3 billion in 2017 dollars). For example, the number of people with ID/DD getting Medicaid-funded supports in home and community-based settings exploded from 22,869 people to 860,500 people.

"Any time you segregate anybody away from the community it's still like being in an institution. An institution is any place you do not have control over your life or make your own decisions."

-- Tia Nelis

Each state makes different choices about how to use tax dollars to pay for supports for people with ID/DD. Thus, the amount of money spent on supports for people with ID/DD varies across states. However, most spending has shifted from institutions to community settings. Most people with ID/DD live in homes in the community, not in institutions. The number of people with ID/DD who receive paid support and do not live with a family member more than doubled between 1987 and 2017. By 2017, most people with ID/DD not living with a family member lived in homes shared by six or fewer people with ID/DD.

In summary, people with ID/DD want:

- Homes of their own, not institutions
- Jobs and meaningful ways to spend their days
- Access to funded supports

- Access to easy-to-use technology



Learn more about individuals with intellectual and/or developmental disabilities [here](#).²¹

There were many years I had to fight just to be in the community ... and not end up back in an institution.” – Heidi Myhre

Events and Situations that Lead to Long-Term Care

Trainer’s Note: The other ~10% not listed in the statistics below are residents who come from psychiatric hospitals, inpatient rehabilitation facilities, long-term care hospitals, hospice, etc.

Nearly 80% of nursing facility residents come from an acute care hospital and require some short-term skilled care such as physical therapy, wound care, or IV medication. Only 9.4% of residents enter a nursing facility from the community.²²

There are several reasons individuals enter a nursing facility or a residential care community. These include but are not limited to:

- A sudden medical event
- The progression of dementia
- The progression of a chronic or a terminal illness

Individuals sometimes decide to go to a long-term care facility due to the recommendation from a physician, or concerns raised by family members.

A medical event

Sometimes a medical event prompts consideration of a long-term care facility. In some cases, a medical event can lead to an individual suddenly and unexpectedly needing long-term care. Even when the harm is low from a medical event, having that experience may cause a person to become fearful of living alone and that fear may be the driving factor to enter a long-term care facility.

Examples of medical events include accidents, strokes, and falls.

- Accidents can lead to paralysis, brain injury, fractures, chronic pain, and more. Some accidents are a result of the progression of dementia (e.g., the individual leaves the stove on and a fire starts).

²¹ Administration for Community Living: *30 Years of Community Living for Individuals with Intellectual and/or Developmental Disabilities*

<https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/30%20Years%207-13-21.pdf>

²² Minimum Data Set 3.0 Frequency Report <https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/Minimum-Data-Set-3-0-Public-Reports/Minimum-Data-Set-3-0-Frequency-Report>

- Strokes are another example of a medical event that could lead to long-term care. Strokes can cause memory loss, paralysis, and/or an inability to verbally communicate.
- Falls can also be a signal for individuals and family members that the individual's health is declining, and more assistance is needed. Falls can cause fractures, brain bleeds, paralysis, traumatic brain injury, internal bleeding, pain, and more.



Alison Parker

I am 45 years old and was in a car accident and almost died. I woke up from a coma 2 months later in the hospital and was told I have a traumatic brain injury. I was discharged from the hospital to the nursing facility for physical and speech therapies. I still struggle with my memory and speech and my right side is also affected from the brain injury; but I am working on getting stronger. I rely on others to help me with my activities of daily living, but I'm getting better. I can brush my teeth and feed myself, but I need someone to set everything up for me. I cannot completely wash myself or get dressed on my own. I am working with the facility to help me find a place to live in the community.

The progression of Alzheimer's disease or other dementias

The progression of Alzheimer's disease or other dementias is overwhelming for individuals and caregivers and often leads to consideration of long-term care.

Alzheimer's disease and other dementias can cause:²³

- Memory loss
- Disorientation
- Confusion
- Delusions or hallucinations
- Behavior changes
- Difficulty eating or swallowing
- Difficulty speaking
- Weight loss
- Wandering
- Incontinence

Although supports and services may be in place, the progression may become more than caregivers can manage at home.

²³ Alzheimer's Association www.alz.org


Bernie Ford

My father lived at home with his wife until she passed away. After she died, it became clear that his dementia was much worse than I had thought. His wife did everything for him and tried not to worry me with the worsening symptoms of Alzheimer's. My father moved in with me and after 6 months, I knew I was in over my head. He began wandering in the middle of the night and a couple of times was brought back to my home by the neighbors. At times he would hallucinate and become combative due to fear and confusion. I knew I could no longer manage his care. I found an assisted living facility for him that specializes in memory care.

The progression of chronic or terminal illnesses

The progression of chronic or terminal illnesses such as cancer, congestive heart failure, liver disease, diabetes, COPD (chronic obstructive pulmonary disease), ALS (Lou Gehrig's disease or amyotrophic lateral sclerosis), MS (multiple sclerosis), renal failure, and others can cause symptoms that cannot be managed without long-term supports and services. Some of these illnesses can lead to severe pain, fatigue, extreme weight loss, and muscle wasting.


Carolyn Dunn

I moved into the nursing facility because I have COPD and struggle with breathing. One afternoon, I had a terrible coughing episode and passed out in my home. As luck would have it, my son happened to stop by and found me laying on the floor. I went to the hospital and was told my lungs are damaged. I need help and I'm too scared to live alone so I decided to move to a nursing facility. My doctor agreed with my decision, and I know my son feels better now that I'm not alone.

Why Do People Continue to Live in Long-Term Care

Facilities?

Many, but not all, residents who receive skilled care stay for a short time and are able to return to their home after they have improved. Others may choose to go to a residential care community (RCC) rather than return home. Those who are unable to do either continue to stay in the nursing facility.

Some reasons individuals do not return home include:

- The resident's health declined or did not improve enough to go home, even with home care services.
- The resident does not have available supports and services to successfully live at home alone.

- The resident has a need for care services and does not have a home to return to. For example, the resident:
 - Lost their home because of financial hardship
 - Had to give up their apartment to pay for their nursing care
 - Was homeless prior to entering the facility

This will be discussed more in Module 4, but even when a resident encounters barriers to returning to their home or a community setting it does not mean they have no other options. Nursing facilities are required to ask all residents if they would like to receive information on how to return to a community setting and, if so, connect the resident to resources that can help them transition out of a nursing facility.

Depending on the state licensure and type of care provided in residential care communities, residents in RCCs may be more independent and physically healthier than those living in a nursing facility. Their reasons for living in an RCC vary and may be different than for those living in a nursing facility.

Some reasons include:

- Feelings of loneliness and isolation
- The RCC meets the specific needs of the resident
- The RCC fills the gap between living independently and living in a nursing facility
- The state has increased opportunities for Medicaid to pay for services provided in RCCs through Home and Community-Based Services (HCBS) waiver programs (discussed more in Module 4)

Section 3:

The Resident Experience

Quality is about meaningful interactions and relationships. There was an extraordinary aide, Jan, who worked overnight and regularly came in to awaken me at about 6:15 a.m. She started the one cup coffee maker, reset the thermostat in the room, and smiled as she left the room telling me, “Have a good day.” It is the little things in life that matter – meaningful interactions and relationships. - Terry

Trainer's Note: Allow at least 45 minutes for Section 3.

When Residents Enter Long-Term Care



Activity: Daily Routines and Activities

Trainer's Note: Allow about 15 minutes for this activity. The time frame will depend on your class size.

This activity allows trainees to think about the experience of moving into a long-term care facility. It asks them about their own personal routines and daily activities and what they would not want to give up if they had to move to a nursing facility tomorrow.

Step 1 - Tell the trainees to **write down their daily routines and activities** and give them a few minutes to do so.

Step 2 - Tell the trainees **they are going to live in a nursing facility tomorrow, and they must cross off all but one daily routine or activity**. That is the routine or activity they get to keep while living in the nursing facility.

If conducting the session virtually, consider the number of trainees and the ability of the trainees to provide verbal responses. If they are unable to respond verbally, they can enter them into the virtual platform (e.g., via a chat box).

Step 3 - Start with your own example then **ask each trainee to tell the group which activity they have chosen**.

Step 4 - You may choose to keep a running visual list or not. Once all trainees have answered the first question, ask them to **look at their daily routines and activities again, including other people involved regularly in their routines**. Ask the three bulleted questions below (and in the PowerPoint Slide) to the entire class and acknowledge/process their responses (all trainees do not need to share their response).

- Why are your routines important to you?
- Should you have to give up your daily routines?
- If you had to modify your routines, what would make the transition easier?

Step 5 - Then ask the trainees to **picture the personal possessions in their home that are most important to them and ask them to start writing them down**. Allow a few minutes to do so.

Step 6 - Tell the trainees to **cross off all but three items** and those are the possessions they can take with them to the nursing facility.

Step 7 - Again, start with your example then allow for all trainees to share their choices. Once everyone has answered, ask the three bulleted questions below (and in the PowerPoint Slide) to the entire class and acknowledge/process their responses (all trainees do not need to share their response).

- Why are your possessions so important to you?
- Should you have to give up all but three of them?
- What would help ease you into your new surroundings without your familiar and beloved possessions?

Step 8 - After everyone has responded, ask them **“What did it feel like to have to choose only a few of your items and one routine?”**

As you work your way through the material in this Module, use the examples given by the trainees to point out the uniqueness of the individuals and the importance our preferences play in the overall quality of life.

Explain to the trainees that the activity was intended to give you an idea of how life-altering moving into a long-term care facility can feel. However, it is important to know that due to federal and/or state requirements long-term care facilities are supposed to provide resident-centered care and honor residents' rights (e.g., respecting resident choices and preferences for their care and routines). This will be discussed more in Module 3.

Consider your thoughts and feelings stimulated by the activity. Think about all the changes people make when they move into a long-term care facility and the effect changes have on them. It's not surprising that the move into a long-term care facility can be extremely difficult, often resulting in feelings of grief and loss.

Experiences of Loss

Trainer's Note: Before you start this part of the training, read the following paragraph. If someone does step out, check in with that individual privately, after the session or at the next break.

Sometimes a discussion of loss and grief can bring up your own personal feelings of past experiences. The training content is not intended to make you feel sad or uncomfortable. However, if something is triggered and you need to step away, please feel free to do so.

Loss and grief – What do those words mean to you?

Trainer's Note: Give the trainees time to think about and to share what these words mean, even if the room is quiet for a bit. Remind them of the feelings they just expressed during the previous activity. Tell them their reactions are no different than those of people entering long-term care.

When you get rid of your house, everything, it is a horrible thing and hard to get adjusted to. They have given me kind words. - Bobby

Feelings of loss are often associated with life-changing events, such as moving to a nursing facility or other long-term care setting. However, when most people think of loss, they think of death, but death is not the only loss that people need to grieve.

Residents have experienced significant losses in a short period of time which can have damaging effects on their physical and mental wellness. Look at the chart below to review some of the major

losses people experience when moving into a long-term care facility and the effects it may have on their health and wellness.

Trainer's Note: Go over the Figure 2 chart and connect the "Possible Effects" to the trainees' responses shared in the activity above. Use the narrative in the trainer's notes below to guide you through the chart. Give examples from your experience working with residents or use the examples provided in the trainer's notes featuring a resident named "Jane."

EFFECTS OF LOSS ON RESIDENTS

Figure 2

Loss	New Circumstances	Possible Effects
Health	Coming to terms with managing a new or worsening illness and/or disability	Feeling anxiety, fear, frustration, anger, despair
Home	Moved (voluntarily or involuntarily) away from a familiar home or setting to an unknown, unfamiliar place	Feeling uneasy, anxious, confused on whereabouts
Family, Friends, Neighbors	Separated from loved ones whom you lived with or visited often - perhaps the resident's partner or caregiver passed away	Feeling sad, lonely, forgotten, isolated, missing loved ones
Freedom	Adjusting to new routines and activities, and feeling that you must conform to a new environment with new rules and guidelines	Feeling frustrated, angry, hopeless, loss of control over daily life; having no autonomy, feeling like a child again

Privacy	Possibly sharing a room with a stranger, staff walking in and out, people asking personal questions, staff may assist you with bathing, dressing, and/or taking you to the bathroom	Feeling humiliated, embarrassed, loss of dignity, frustration, anger
Personal Property	Loss of personal belongings with special meaning or memories	Feeling disconnected

Loss of health: Loss of health is often the reason someone enters a long-term care facility. With loss of health, one may struggle with coming to terms with managing a new or worsening illness and/or disability. Loss of health can cause feelings of anxiety, fear, frustration, anger, or despair.



Example: Jane had trouble with her balance while living alone in her apartment. She had a few falls, but the last fall resulted in a broken hip. She is now receiving physical therapy in a nursing facility. She is afraid of being alone and falling again, but at the same time, she is angry at her limited mobility. She has always been very independent and can't bear to think about not living life as she did prior to breaking her hip.

Loss of home: Every person in a long-term care facility has left their previous home and now may be living in an unknown and unfamiliar setting. Residents can feel a sense of uneasiness, anxiousness, and even confusion about their surroundings. Many may feel uncomfortable in their new home.



Example: Jane has a hard time relaxing in the nursing facility with all the commotion going on in the halls. She doesn't sleep well because her bed is not as comfortable as her bed at home. When she does fall asleep, she wakes up confused. Jane is at risk of losing her senior housing if she stays in the nursing facility much longer and she has a great deal of anxiety about it.

Loss of family, friends, and neighbors: Most people in long-term care are newly separated from their loved ones. Not just those who lived in the same home, but friends and neighbors as well. Some residents enter a long-term care facility because the person taking care of them passes away. When people lose someone they love, whether through death or separation, it can be devastating and may bring about feelings of sadness, loneliness, isolation, and missing loved ones.



Example: When Jane lived in her apartment, she played cards with four friends from her floor every Tuesday night. Most were single, without a lot of family around, so the five of them became each other's family. Jane's friends rely on

public transportation and the nursing facility isn't in a convenient area for them to visit. She misses them terribly.

Loss of freedom: Individuals go from making all decisions about their daily life to adjusting to new routines, scheduled and non-scheduled activities, and the confines of living in a facility with new rules and guidelines. No longer living on one's own can lead individuals to feeling frustrated, angry, hopeless, and/or a loss of control over their daily life. Having no autonomy and being told what to do can make one feel like a child again.



Example: *Jane feels very frustrated and angry with her new set daily schedule. She used to sleep in and slowly get out of bed, make her coffee, and have toast with jam. Sometimes she would invite her friends over mid-morning for coffee and cookies. In the evening she liked to eat dinner and watch her shows. At 9:00 p.m. every night, Jane would take a bath, then make herself a bowl of ice cream and eat it in bed while watching the news. Now, staff get her up early to go to physical therapy, then take her to breakfast where she is served too much food. She feels guilty if she doesn't eat it, but she just wants some toast and coffee and quiet time in her room. Jane only gets showers twice a week at 11:00 a.m. Her roommate's TV is too loud for Jane to watch her evening shows and since her roommate was there first, Jane is uncomfortable asking her to turn her TV down. Jane feels as though her life is now all on the facility's schedule and feels a complete loss of control over her own life.*

Loss of privacy: Most residents share a room with a stranger. All residents deal with staff walking in and out and asking very personal questions. In addition, some residents have strangers washing and dressing them and taking them to the bathroom. These are very intimate acts and can lead to feeling humiliated, embarrassed, frustrated, angry, and even feeling a loss of dignity.

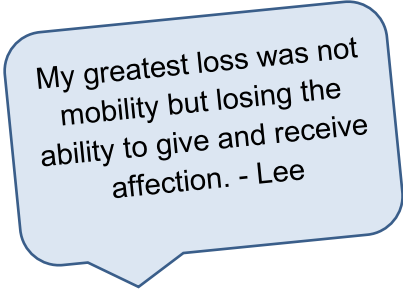


Example: *When Jane lived alone, she was used to taking care of herself. She likes her roommate in the nursing facility and enjoys their conversations, but she feels so humiliated and embarrassed when staff assist her in the shower and in the bathroom, especially when the male aides help her. It makes her feel sick to her stomach every time she needs assistance in the bathroom or shower.*

Loss of property: Residents can only bring a few personal items when they move in. Often, personal items or possessions make people feel a sense of belonging or may remind them of special memories. Without those items some people feel disconnected from their former life.



Example: *Jane has a special clock that was handed down to her from her grandparents. The clock chimes every hour, and the sound always reminds her of her childhood. She misses her clock and the memories it brought to her.*



My greatest loss was not mobility but losing the ability to give and receive affection. - Lee

To manage feelings of loss, individuals must grieve those losses. Feelings of grief and loss can cause some residents to respond in a manner which may be perceived as being “difficult.” When a resident experiences multiple, significant losses in a short period of time, it can impact the resident’s ability or desire to: be involved with decisions related to their care; develop new relationships; accept help; eat; and/or sleep.

Representatives are not social workers or therapists and should not act in such a manner. The purpose of understanding grief and loss is to consider whether a specific loss or the grief process is at the core of an issue which helps weigh options in the problem-solving process. This also offers opportunities for you to promote, and advocate for, facility practices that embody resident-centered care, such as choice in daily routines, rather than residents following routines of the staff and facility.

What Residents Say About Living in Long-Term Care

Residents have the right to know when and why a medication or dosage has been changed. - Louella

There is one charge nurse that upsets everyone in the dining room. She treats us like kids. - Karen

Don't answer call lights. I have sat on the pot for an hour. - John

The staff think they have authority over you. - Mickey

Staff don't like to have to lift people. - Otis

So, what makes a good day for you here in the nursing home?

When I wake up and I get my cup of caffeinated coffee. I get hot water for caffeinated coffee, I have instant coffee and that makes my day, my caffeinated coffee. I go to breakfast, a lot of people don't but I'm able to and if there is some activity going on that I especially like, like cards or bingo, or a nice amusement and then if I have a nice supper and then I usually go to bed early, I watch television, Wheel of Fortune, Jeopardy. - Fran

What's important to you in a day?

Um, getting up early, which I've had a tough time convincing them that that's what we need. Um, having breakfast in the morning, that's good. I have time after breakfast to do some physical therapy if I could find someone to help me. Um, which is about always available most of the time. And then it's sitting outside with some friends, breathing in the good air, or going upstairs and watching TV or reading, all those exciting things. Then it's lunch and then you go back to, going outside, and if you get tired of that, then you go back upstairs to your room, watch TV, and read, come down for dinner and when that's done, you go outside and you go upstairs, you watch TV or read. - Jessica

Section 4:

Common Health Experiences

I don't ever want to be in a nursing home, I used to say. I fell and broke bones, went to the nursing home, went home, fell again, went back to the nursing home.

I need to be in a nursing home - I want to be in a nursing home.

- Betty

Common Physical Health Diagnoses and Their Importance to the Ombudsman Program

***Trainer's Note:** Allow at least 60 minutes to cover Section 4. Explain the common diagnoses and their importance to the LTCOP. As mentioned below, remind trainees that this section is intended to enhance their understanding of these common mental and physical health conditions and needs. However, it is important to remember that each resident has unique needs and preferences related to their experiences living with chronic illness and/or disability and are entitled to receive individualized, resident-centered care. To provide resident-directed advocacy, representatives must understand individual needs and preferences.*



***Optional Prework:** You may consider asking trainees to read Section 4 prior to training. Section 4 includes a lot of detailed information, so it may be helpful for trainees to read it prior to classroom discussion.*

Individuals living in long-term care facilities need a variety of supports and services related to their diagnosis or diagnoses. Most people living in long-term care facilities are there not because of the diagnosis, but because they cannot manage their illness or illnesses on their own. Many residents have more than one illness.

Residents who experience chronic illness and/or have a disability have unique needs and ways of living with their condition(s). It is important to see the person, not the disease or disability, and to understand individual needs and preferences in order to provide resident-directed advocacy. In addition to understanding the resident's individual experiences, needs, and preferences related to their diagnoses and/or disability, it is important to know how they want to be acknowledged. Module 3 will discuss person-first and identity-first language.

According to resident data, some of the most common physical health diagnoses in nursing facilities include hypertension (high blood pressure), hyperlipidemia (high cholesterol), diabetes, heart disease, and arthritis. Although the common physical health diagnosis discussed in this section are based on data from nursing facilities, residents in RCCs often have similar chronic health issues.

Hypertension: Why is this important information for the LTCOP?

Residents may have concerns about their health and whether the facility staff are appropriately providing the medication, diet, exercise, and stress reduction necessary for them to remain as healthy as possible. On the other hand, residents may wish to go against doctor's orders and ask you to advocate on their behalf to eat whatever they want, to decline their medication, or to not engage in physical activity.

Heart Disease & High Cholesterol: Why is this information important for the LTCOP?

Some residents with a history of heart attack have expressed fear and anxiety. For example, residents may worry they could have a heart attack, and no one will come in time. The LTCOP may advocate for residents to keep their nitroglycerin tablets in their room.

Hypertension

Commonly referred to as high blood pressure, hypertension is the most common diagnosis of long-term care residents. High blood pressure can lead to severe health complications, including heart disease, stroke, and even death. High blood pressure can be treated through medication, diet, and exercise as well as stress reduction.²⁴

We've talked about the role of the LTCOP and taking resident direction, but not focusing on best interest. At times, by following resident direction the LTCOP may advocate for something we think is not best for the resident.

If a resident wants to go against doctor's orders, how would you start that conversation with the nurse?

Trainer's Note: *Start with obtaining permission from the resident to talk to the nurse. Ask the resident if they are comfortable talking with the nurse while you are there and encourage the resident to explain why they want to go against doctor's orders. If the resident does not want to talk to the nurse with you, relay the resident's concerns and desired outcomes in their own words. For example, say, "the resident told me the medicine makes him too groggy, and he barely remembers visits with his family." As opposed to saying, "the resident wants to stop taking his medication."*

Heart Disease & High Cholesterol

Heart disease²⁵ describes a range of conditions affecting the heart that involve narrowing or blocking of blood vessels. Such conditions can lead to heart attack or stroke. Other heart conditions affecting the heart's muscle, valves, or rhythm are also considered to be forms of heart disease. Heart disease and high cholesterol are significant

²⁴ Healthline: *Everything You Need to Know About High Blood Pressure (Hypertension)*
<https://www.healthline.com/health/high-blood-pressure-hypertension>

²⁵ Mayo Clinic retrieved from <https://www.mayoclinic.org/>

diagnoses in long-term care residents. Both can be treated through diet, exercise, a healthy lifestyle, and medication.

Often heart disease is viewed only as a physical condition. However, according to the National Institutes of Mental Health, up to 65% of people with heart disease and a history of heart attack experience various forms of depression.

Trainer's Note: *If the question is asked, yes, a resident may be allowed to keep medication in their room if they are able to manage it but don't go into details about that issue. It can be addressed during the care plan module. Nitroglycerin is a medication that is often prescribed to help stop chest pain.*

Diabetes

Diabetes²⁶ is a disease in which the body's blood sugar (glucose) is too high. Insulin is the hormone that helps blood sugar get into cells. Type 1 diabetes occurs when the body does not make insulin. Type 2 diabetes is more common and occurs when the body does not make or use insulin well. When there is not enough insulin, too much glucose stays in the blood and overtime, too much glucose can lead to serious health problems affecting one's eyes, kidneys, and nerves.

People with Type 1 diabetes take insulin to control their blood sugar. Type 2 diabetes is treated through diet, exercise, and sometimes medication and/or insulin. The term "brittle diabetes" may be used to describe uncontrolled diabetes with drastic swings between too high or too low blood sugar. Some people may refer to their "sugars" when talking about diabetes or their sugar levels.

Arthritis

Arthritis²⁷ is the swelling and tenderness of one's joints. The main symptoms of arthritis are joint pain and stiffness that can worsen with age. Some residents have severe and painful arthritis that impacts their daily life. Treatments are used to reduce the pain and symptoms and improve quality of life.

Diabetes: Why is this important information for the LTCOP?

The LTCOP often works with residents who have concerns related to the management of their diabetes. Residents consider not just their health, but their quality of life.

Such concerns may include:

- Uncontrolled blood sugar levels.
- Insulin not checked per doctor's orders.
- Proper diet not being served.
- Facility not honoring the resident's right to decline dietary restrictions.
- Possible amputation.

²⁶ NIH National Institute of Diabetes and Digestive and Kidney Diseases retrieved from <https://www.niddk.nih.gov/>

²⁷ Mayo Clinic retrieved from www.mayoclinic.org

The two most common types of arthritis are osteoarthritis and rheumatoid arthritis (RA).²⁸

Osteoarthritis (OA) is the most common form of arthritis (over 32.5 million adults in the United States have OA). Some people call it degenerative joint disease or “wear and tear” arthritis. It occurs most frequently in the hands, hips, and knees.

With OA, the cartilage within a joint begins to break down and the underlying bone begins to change. These changes usually develop slowly and get worse over time. OA can cause pain, stiffness, and swelling. In some cases, it also causes reduced function and disability; some people are no longer able to do daily tasks or work.

Rheumatoid arthritis (RA) is an autoimmune and inflammatory disease, which means that your immune system attacks healthy cells in your body by mistake, causing inflammation (painful swelling) in the affected parts of the body.

RA mainly attacks the joints, usually many joints at once. RA commonly affects joints in the hands, wrists, and knees. In a joint with RA, the lining of the joint becomes inflamed, causing damage to joint tissue. This tissue damage can cause long-lasting or chronic pain, unsteadiness (lack of balance), and deformity (misshapeness). RA can also affect other tissues throughout the body and cause problems in organs such as the lungs, heart, and eyes.

Arthritis can be very debilitating, both physically and mentally. The pain and restrictions of arthritis can make it difficult to perform daily tasks. Due to the pain and restrictions related to arthritis some individuals are more susceptible to developing anxiety and depression.

It's important to remember that the Ombudsman program does not serve as a source of medical advice or expertise (even if a representative has such expertise) but serves to represent resident concerns and ensure that the resident has access to medical information and their health care providers.

While advocating for appropriate treatment and care, talk about the concern from the resident's perspective. For example, instead of saying, “the resident needs more appropriate treatment,” you could say, “the resident is telling me that her pain medication is not working.”

²⁸ Information regarding OA and RA is from the Centers for Disease Control and Prevention (CDC), Arthritis Types, <https://www.cdc.gov/arthritis/basics/types.html>

Cognitive Disorders, Mental Health, and Their Importance to the Ombudsman Program

Some residents have illnesses such as cognitive disorders and mental health disorders. While you can't see cognitive disorders and mental illness, both can be very debilitating. Some people cannot manage their cognitive disorder or mental health disorder and require the supports and services of long-term care.

Dementia²⁹

Dementia is a general term for a decline in memory, reasoning, or other thinking skills that interferes with daily life. There are many different types of dementia. Over half of residents in nursing facilities have a diagnosis of dementia or Alzheimer's disease. Dementia is not a normal part of aging.

Dementia is not a single disease. It's an overall term — like heart disease — that covers a wide range of specific medical conditions, including Alzheimer's disease. Disorders grouped under the general term "dementia" are caused by abnormal brain changes. These changes trigger a decline in thinking skills, also known as cognitive abilities, severe enough to impair daily life and independent function. They also affect behavior, feelings, and relationships.

Treatment for dementia depends upon the cause of the dementia. There are many conditions that can cause symptoms of dementia and some of those conditions are reversible.

The Ombudsman program works with and takes direction from residents living with dementia to the extent that they can provide direction. Often, others prematurely take charge and make decisions for residents with Alzheimer's or dementia without the input of the resident. The representative may be the only person who brings the resident's wishes to the table.

Dementia: Why is this important information for the LTCOP?

Residents with dementia may have escalated symptoms related to their dementia in response to their environment. They may feel fearful, hurt, confused, or even experience delirium. Behavioral symptoms may be the only way residents are able to communicate their feelings. **It is important to remember that behavior is communication.**

The key is figuring out the root cause. The LTCOP can work with the resident, facility staff, and other members of the resident's support system to develop a person-directed care plan to meet the resident's needs.

²⁹ Most of the information below for dementia and Alzheimer's Disease is from The Alzheimer's Association, *Dementia vs. Alzheimer's Disease: What's the Difference?* <https://www.alz.org/alzheimers-dementia/difference-between-dementia-and-alzheimer-s>

Alzheimer's Disease

Alzheimer's disease is the most common cause of dementia, accounting for 60-80% of dementia diagnoses. Alzheimer's disease is a deteriorating brain disease that is caused by cell damage. It leads to dementia symptoms that gradually worsen over time. The most common early symptom of Alzheimer's is trouble remembering. As Alzheimer's advances, symptoms get more severe and could include disorientation, confusion, behavior changes, weight loss, incontinence, delusions, or hallucinations. Eventually, speaking, swallowing, and walking become difficult.

There is no way to prevent, cure, or even slow Alzheimer's disease. However, there are several treatment options to help manage the symptoms of the disease including medications for memory and treatment for behavior and sleep changes.³⁰

***Trainer's Note:** Don't go into too much detail here with complaint resolution. The point is that you can take direction from each resident below regarding these concerns regardless of their memory problem. You can provide your own examples of working with and taking direction from someone with dementia or use the examples here.*

Many people have questions about the LTCOP taking direction from someone living with Alzheimer's disease or dementia. Here are two examples of situations in which the LTCOP may assist.

Example: Greta says she feels scared at night when they turn all the lights off in her room.

Example: Doris complains that someone stole her ring, and she wants it back.

Regardless of their diagnosis, the LTCOP can talk to staff with each resident's permission to resolve their concerns.

***Trainer's Note:** Show the video below and let the trainees know the video was made to inform residents about Alzheimer's disease and dementia. At the end of the video advance directives are mentioned. Let the trainees know advance directives are discussed in Module 3.*



Watch the video titled [LTC Informational Series Video 7 Addressing Dementia in Long-Term Care Facilities](https://www.alz.org/alzheimers-dementia/difference-between-dementia-and-alzheimer-s)³¹ to summarize the discussion about Alzheimer's disease and dementia.

According to the video, what statements are true about people living with dementia?

1. The person may not remember who or where they are.

³⁰ The Alzheimer's Association <https://www.alz.org/alzheimers-dementia/difference-between-dementia-and-alzheimer-s>

³¹ Southwestern Commission, LTC Informational Series Video 7 - Addressing Dementia in Long-Term Care Facilities, https://www.youtube.com/watch?v=W6ILW0kHA9M&list=PLSu_zY6vP6REXfvjgVf7E-F9CG2K_9P-F&index=7

2. All individuals living with dementia are alike.
3. Residents with dementia need advocates.

Answer: Numbers 1 and 3 are true. Number two is false – no two individuals with dementia are alike.



Learn more about [dementia and Alzheimer's disease](#).³²

Mental Illness³³

Mental illnesses are health conditions involving changes in emotion, thinking, or behavior (or a combination of these). Mental illnesses are associated with distress and/or problems functioning in social, work, or family activities.

Mental illness is common. In a given year:

- Nearly one in five (19 percent) U.S. adults experience some form of mental illness
- One in 24 (4.1 percent) has a serious mental illness
- One in 12 (8.5 percent) has a diagnosable substance use disorder

Mental illness is treatable. Most individuals with mental illness continue to function in their daily lives. People living with mental illness reside in the community-at-large and in long-term care settings. Some residents with mental illness are in long-term care facilities because community services and supports to help manage their symptoms and/or medication are not available.

Serious Mental Illness: Why is this important for the LTCOP?

Working with residents who have a diagnosis of a serious mental illness may present a challenge if there are barriers in communication, or if the resident's concern is not one you can verify or resolve.

Most long-term care staff do not have proper training on SMI. Due to a lack of staff training and the residents' potential responses, residents with a serious mental illness may be at a greater risk for being discharged from the facility against their wishes.

Serious Mental Illness (SMI)³⁴

A mental illness that interferes with a person's life and ability to function is called a serious mental illness (SMI). With the right treatment, people with SMI can live productive and enjoyable lives.

There are many kinds of serious mental illness. Common types include:

³² The Alzheimer's Association <https://www.alz.org/alzheimers-dementia/what-is-dementia#symptoms>

³³ Adapted from American Psychiatric Association, What is Mental Illness? <https://www.psychiatry.org/patients-families/what-is-mental-illness>

³⁴ Adapted from the U.S. Department of Health & Human Services, Substance Abuse and Mental Health Administration (SAMHSA), Living Well with Serious Mental Illness. <https://www.samhsa.gov/serious-mental-illness>

Bipolar disorder -- a brain disorder that causes intense shifts in mood, energy, and activity levels. People have manic episodes in which they feel extremely happy or euphoric, and energized. Usually, they also have depressive episodes in which they feel deeply sad and have low energy.

Major depressive disorder (MDD) -- one of the most common mental disorders. Symptoms vary from person to person, but may include sadness, hopelessness, anxiety, pessimism, irritability, worthlessness, and fatigue. These symptoms interfere with a person's ability to work, sleep, eat, and enjoy their life.

Schizophrenia -- a chronic and severe mental disorder that causes people to interpret reality abnormally. People may experience hallucinations, delusions, extremely disordered thinking, and a reduced ability to function in their daily lives.

Despite common misperceptions, having a serious mental illness is not a choice, a weakness, or a character flaw. It is not something that just “passes” or can be “snapped out of” with willpower. The specific causes are unknown, but various factors can increase someone's risk for mental illness including, family history, brain chemistry, and significant life events such as experiencing a trauma or death of a loved one.



Learn more about living with [serious mental illness](https://www.samhsa.gov/serious-mental-illness).³⁵

***Trainer's Note:** Discharge is referenced in the text box on the right. No need to get into a discussion about discharges at this point in the training; transfer and discharge are discussed in more detail later.*

Depression

Depression is also called depressive disorder, or clinical depression, and is a mood disorder. Depression is a constant loss of interest or pleasure in normal activities that lasts for at least two weeks and significantly interferes with a person's daily activities. Unfortunately, over one-half of nursing facility residents are diagnosed with depression. Depression can be treated with medication and various forms of therapy.³⁶

Depression symptoms can vary from mild to severe and can include:³⁷

- Feeling sad or having a depressed mood
- Loss of interest or pleasure in activities once enjoyed

Depression: Why is this important information for the LTCOP?

It is important to attempt to visit residents who seem withdrawn and tend to stay in their room. It may take multiple visits, but the resident may share their experiences if they believe you are willing to take time to be present with them and listen.

Sometimes just sitting quietly with a resident can be helpful.

³⁵ <https://www.samhsa.gov/serious-mental-illness>

³⁶ Mayo Clinic <https://www.mayoclinic.org/diseases-conditions/depression/symptoms-causes/syc-20356007>

³⁷ American Psychiatric Association <https://www.psychiatry.org/patients-families/depression/what-is-depression>

- Changes in appetite — weight loss or gain unrelated to dieting
- Trouble sleeping or sleeping too much
- Loss of energy or increased fatigue
- Increase in purposeless physical activity (e.g., inability to sit still, pacing, handwringing) or slowed movements or speech (these actions must be severe enough to be observable by others)
- Feeling worthless or guilty
- Difficulty thinking, concentrating, or making decisions
- Thoughts of death or suicide

Many residents experience a feeling of sadness or grief at one time or another. Clinical depression is more than a feeling of temporary sadness and one cannot simply get better by changing one's attitude. Residents with a diagnosis of depression may choose not to seek assistance from the LTCOP or may stay in their room or sleep often during LTCOP visits. Such residents may be hard to reach.



Learn more about [depression](#).³⁸

Anxiety Disorders

People with anxiety disorders experience persistent, excessive fear or worry in situations that are not threatening.³⁹ There are various types of anxiety disorders, and each has its own specific symptoms and treatments. According to the National Alliance on Mental Illness (NAMI), typical symptoms of anxiety disorder can be broken into two groups - emotional symptoms and physical symptoms.

Emotional Symptoms

- Feelings of apprehension or dread
- Feeling tense or jumpy
- Restlessness
- Irritability
- Anticipating the worst
- Being watchful for signs of danger

Physical Symptoms

- Pounding or racing heart and shortness of breath

Anxiety Disorders: Why is this important information for the LTCOP?

Residents with anxiety disorders often have issues related to trust and may not believe you are able or willing to make a difference. They may be agitated and have a hard time focusing on the issue at hand.

Representatives should be honest, relatable, and respectful to build a trusting relationship.

³⁸ American Psychiatric Association <https://www.psychiatry.org/patients-families/depression/what-is-depression>

³⁹ National Alliance on Mental Illness retrieved from www.nami.org

- Sweating, tremors, and twitches
- Headaches
- Fatigue and insomnia
- Upset stomach
- Frequent urination, or diarrhea

In closing, it is important to understand that mental illness is treatable. Treatment varies depending upon the diagnosis and individualized plan. With early and consistent treatment individuals with serious mental illness can lead meaningful, productive lives.⁴⁰

Other Health Concerns

***Trainer's Note:** Follow the PowerPoint when discussing falls, incontinence, pain, and pressure ulcers. The statistics provided are to give the trainees an idea of the frequency of each concern presented. Make sure you share your experiences with each of these concerns.*

There are other health concerns that residents may experience while living in a long-term care facility.

Some of those concerns include:

- Falls
- Incontinence
- Pain
- Pressure ulcers

Falls

Falls can have damaging effects on residents from cuts and scrapes, to fractured bones, to brain bleeds, and even death.

Common reasons residents fall include:⁴¹

- Medical conditions (e.g., muscle weakness, dizziness, balance issues)
- Medication side-effects (e.g., lightheadedness, groggy)
- Accidents while moving residents from one location to another (e.g., dropping residents during a transfer between their wheelchair and the toilet)
- Not receiving timely help so the resident attempts to complete the activity on their own (e.g., walk without assistance)
- Hazards and spills on the floor

⁴⁰ Paragraph adapted from two sources. SAMHSA, Serious Mental Illness – Multimedia Resources, <https://www.samhsa.gov/serious-mental-illness/resources> and American Psychiatric Association, What is Mental Illness, <https://www.psychiatry.org/patients-families/what-is-mental-illness>.

⁴¹ Nursing Home Abuse Center retrieved from www.nursinghomeabusecenter.org

While some falls are unavoidable, there are prevention measures facilities can take to lower the likelihood of a fall, such as:

- Conduct fall risk assessments
- Train staff on proper transferring techniques and fall prevention techniques
- Have adequate staff to meet all resident needs
- Ensure equipment used to transfer residents is functioning properly
- Ensure there are no environmental hazards that would cause a resident to slip, trip, or fall
- Offer exercise programs, physical therapy, stretching, and balancing

Incontinence

***Trainer's Note:** Share deidentified case examples to show what it is like for residents to be incontinent and wait for someone to change and clean them. When residents ask for assistance to the restroom some have been told to just go in their bed or incontinence brief. Staff may say, "just go in your bed, I'll clean you up later." This is humiliating and undignified.*

There's no easy or comfortable way to talk about going to the bathroom. There are many terms used casually (e.g., going #1 or #2) and more clinical terms (e.g., urinating, defecating, having a bowel movement). "Stool," "excrement," and "feces" are other terms used to describe the body's waste.

Incontinence means the inability to control urination or defecation. Incontinence is a significant concern that impacts more than one-half of nursing facility residents. Problems associated with incontinence are urinary tract infections (UTIs), other infections, risk of pressure ulcers or skin irritation, as well as feelings of embarrassment and humiliation.

Concerns shared with the Ombudsman program about incontinence include:

- Residents being left in their own waste
- Lack of privacy during incontinence care
- Call lights not answered timely which can lead to accidents
- Residents' clothing or bedding not changed often enough
- Residents not being taken to the bathroom and told to "go in place/go in their brief"

Pain

***Trainer's Note:** Make sure to share the quotes from residents in the sidebar. The quotes came from a project titled "The Effects of the Opioid Crisis on Residents: Points of Advocacy," by the National Long-Term Care Ombudsman Resource Center (NORC), the National Consumer Voice for Quality Long-Term Care (CV), and the National Center on Elder Abuse (NCEA). Face-to-face interviews with residents about opioid use were*

Residents' quotes on pain

"The pain is always there... it will never go away completely."

"Opioid medications are the ones that work best to manage pain."

"...only thing that works is the opioids, but it doesn't always help. Sometimes it takes 1 hour to kick in."

"...meds were not always ordered on time from the pharmacy so may have to go one or more days without treatment."

One resident said she has to be assertive to get her meds—says she "rounds up" staff to get them.

"Sometimes medication isn't effective for entire window of time."

"Was an instance of a nurse diverting fentanyl patches for herself."

conducted. Another questionnaire was sent to Ombudsman programs asking about their experiences on the topic.

Fentanyl is an opioid pain medication. The resident quote in the sidebar on diverting fentanyl patches is referring to a staff member stealing the patch to either sell or to use. The result is that the resident who was prescribed the patch would not receive their pain medication for at least 3 days (or as prescribed).

Many residents experience pain at one time or another, while some experience chronic pain. With pain comes other factors such as loss of appetite, loss of interest in activities, and difficulty sleeping. Pain assessments should be done on a regular basis and as prescribed in the resident's care plan. Treatment for pain ranges from non-medical techniques (e.g., aroma therapy, massage, music therapy) to various levels of pain medications (e.g., over-the-counter medication or prescription medication, including the use of opioids).

While many nursing facility residents are in persistent pain, the pain is often under-treated, and alternatives are not widely available or used. Residents report not being involved or informed of changes of their pain medication. Residents also report delays in getting their pain medication or even missing doses. The most common opioid related complaints are drug diversion (e.g., theft or misuse of resident medication by facility staff) and medication unaccounted for. Residents express a great deal of concern about pain management and

a lack of knowledge about their own treatment and other treatments.

One representative said, *"There have been residents who complain that they don't feel they are getting their pain addressed or getting their pain medicine that helps with their pain."* Another representative stated, *"Residents have reported that they are in so much pain that they have attempted suicide due to their untreated pain. This is very disturbing."*



The National Long-Term Care Ombudsman Resource Center (NORC), the National Consumer Voice for Quality Long-Term Care (CV), and the National Center on Elder Abuse partnered on a study titled “[*The Effects of the Opioid Crisis on Residents: Points of Advocacy*](#)”⁴² where residents were interviewed, and representatives were asked to complete a questionnaire.

Pressure Ulcers

Pressure ulcers, often referred to as pressure sores, decubitus ulcers, or bed sores, are caused by pressure to areas of the skin when resting in one position for too long, thereby restricting blood flow. According to MayoClinic.org,⁴³ “the degree of skin and tissue damage ranges from red, unbroken skin to a deep injury involving muscle and bone.” Pressure ulcers are serious and can lead to infections which may result in death if not properly treated.

Many residents have risk factors to develop a pressure ulcer including:

- Immobility
- Incontinence
- Spinal cord injuries, neurological disorders, etc.
- Poor nutrition and hydration
- Medical conditions affecting blood flow

No Two Residents are Alike

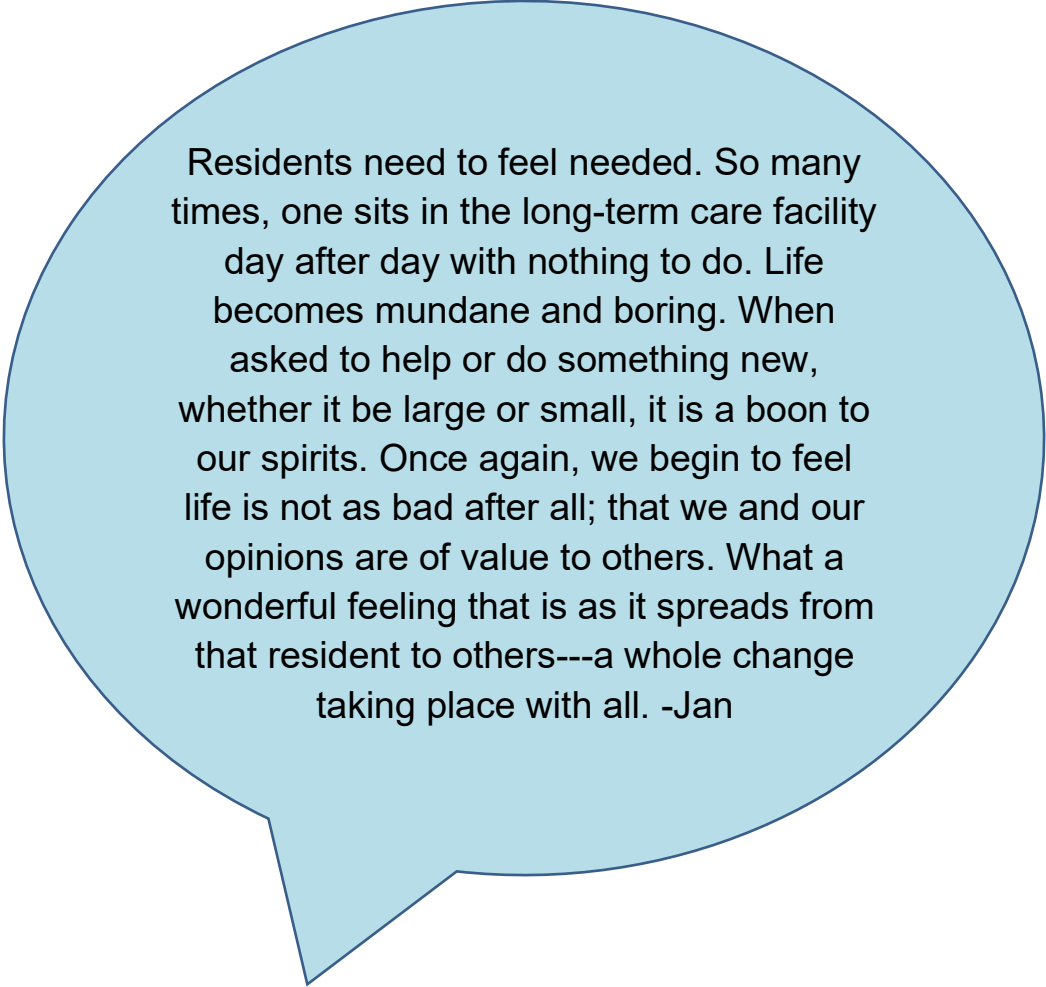
There’s a saying within the Ombudsman program, “If you’ve talked to one resident, you’ve talked to one resident.” Each resident has their own unique background and experience. The key point to take away from this Module is to approach each resident with dignity, respect, and an open mind. While it is important to understand resident demographics, common health experiences, and reasons why individuals receive long-term care services and supports, remember that the resident comes first. Residents are more than their diagnoses and ensuring they receive resident-centered, quality care is your primary goal as a representative.

⁴² <https://ltombudsman.org/issues/pain-management>

⁴³ Mayo Clinic retrieved from: <https://www.mayoclinic.org/diseases-conditions/bed-sores/symptoms-causes/syc-20355893>

Section 5:

Conclusion



Residents need to feel needed. So many times, one sits in the long-term care facility day after day with nothing to do. Life becomes mundane and boring. When asked to help or do something new, whether it be large or small, it is a boon to our spirits. Once again, we begin to feel life is not as bad after all; that we and our opinions are of value to others. What a wonderful feeling that is as it spreads from that resident to others---a whole change taking place with all. -Jan

Module 2 Questions

***Trainer's Note:** Allow at least 15 minutes for Section 5. These questions are meant to determine if the trainees learned the fundamental learning objectives and may illicit discussion about the answers. The questions and answers are not meant to be rushed through.*

1. Select the statements that are true about individuals who live in long-term care facilities. Residents
 - a. May be of any ethnicity
 - b. Are not under the age of 65 years
 - c. Are primarily men
 - d. Are primarily white
 - e. Are primarily over 85 years

***Answers:** The correct answers are, a, d, and e.*

The incorrect answers are b – some residents are under 65; c – most residents are female.

2. Name some reasons people enter long-term care facilities.

***Answers:** A medical event, the progression of Alzheimer's disease or other dementias, the progression of chronic or terminal diseases, loneliness and isolation, the need for supports and services not accessible within the community.*

3. Name some of the losses that residents may experience when they enter a long-term care facility and how those losses affect residents.

***Answers:** Health, home, family, friends, neighbors, freedom, privacy, personal property, dignity. Effects include feelings of anxiety, fear, frustration, anger, despair, sadness, hopelessness, humiliation, embarrassment and/or sense of uneasiness, anxiousness, confusion on whereabouts, uncomfortableness, loneliness, loss of control over daily life, being forgotten, feeling isolated, missing loved ones, feeling like a child.*

4. Name some of the common diagnoses and other health concerns of residents.

***Answers:** Hypertension, Alzheimer's disease or other dementias, depression, heart disease, diabetes, arthritis, bipolar disorder, schizophrenia, anxiety disorder, falls, pressure ulcers, pain, incontinence.*

5. Why is it important for representatives to understand resident experiences?

***Answers may include:** to empathize with the resident's situation, to clarify any myths or preconceived notions, to be prepared for what representatives may encounter.*